

Estimating the broader fiscal impact of rare diseases using a public economic framework: A case study applied to acute hepatic porphyria (AHP)

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Background

AHP is a metabolic disorder where organic compounds called porphyrins accumulate in the liver due to an absence of enzymes of the porphyrin pathway, resulting in acute attacks that lead to neurological symptoms, severe abdominal and back pain and acute polyneuropathy. Due to likelihood of recurrent attacks and associated co-morbidities, people with AHP are often unable to work which increases dependency on public assistance [1].

Healthcare is often measured in direct medical costs to assess economic burden of a condition. However, in many conditions the indirect costs associated with lost productivity can be greater than the costs of treatment. Alternative economic frameworks can be used to understand how a condition impacts government, specifically in relation to lost tax revenue and future disability related and social benefit costs. Apply this "government perspective" provides insights for government in relation to disease burden, priority setting and cross-sectorial impact of health [2].

The aim of this study was to apply a public economic framework taking into consideration a broad range of costs that are relevant to government in relation to transfer payments and taxes paid by people with AHP.

Methods & Data

A fiscal model was developed to assess lifetime tax contributions and government payments received for disability, pensions and healthcare for people with AHP compared to the general population (GP). The model was constructed using average earnings, work activity and retiring age 65. The model annually adjusts for mortality in AHP and GP populations using published life tables for Sweden.

Fiscal inputs were obtained from published sources and from the Swedish Statistical bureau (<https://www.scb.se/>). All data was input as age-specific parameters to evaluate the intertemporal effects of disease progression at different stages of life. Health care costs for attacks and chronic morbidity attributed to AHP. A summary of key inputs are defined in Table 1.

Table 1: AHP fiscal model inputs

Input variable		Source
Wage growth	0.8%	Link SCB
Cost inflation	1.3%	Link SCB
Tax wedge	43.1%	Link OECD
VAT	25.0%	Source Link
Avg. annual state pension	SEK156,000	Pensions Myndigheten
Avg. disability pension	SEK116,664	Social Science Figures

The model also includes costs associated with treating AHP attacks and associated co-morbidities. We applied a cost of SEK46,808 per AHP attack. The annual costs associated with treating co-morbidities for an individual with recurrent AHP attacks was estimated to be SEK298,328 per year.

In this analysis we model a patient scenario as follows: Age of diagnosis at 25, average 12 AHP attacks per year for the duration of life.

Results

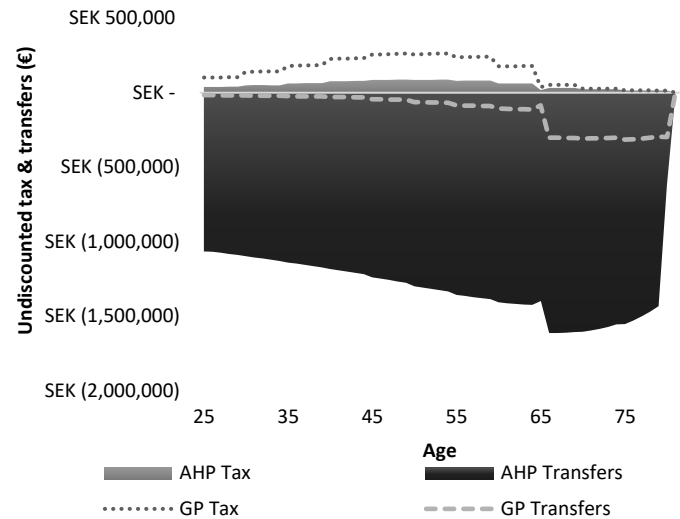
The model estimates impact of AHP on government cash flow from taxes collected and costs associated with healthcare and disability support pensions. These are reflected graphically demonstrating how these transactions change every year. The model starts at age 25 at the point of diagnosis and counts differences in taxes (positive) between AHP and GP person. Additionally, the model calculates government costs (negative) over time for different public programs (e.g., disability, healthcare, pensions).

References & Disclosure

- Neeleman RA, et al. J. of Inherited Metabol. Disord. 2018;41:809-817.
- Connolly MP., et al., Value Health, 2017. 20(2): p. 273-277.

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Figure 1: Fiscal life course for person with AHP diagnosed aged 25 compared to general population (GP) discounted at 3%



The estimate average costs for disability in AHP are SEK3.5 million compared to GP of SEK0.4 million. For all transfers estimated, people with AHP require additional SEK31.9 million compared to the GP. We estimate average reduction in lifetime taxes of SEK2.8 million for people with AHP (Table 2).

Table 2: Base case analysis with diagnosis age 25 experiencing 12 attacks per year until menopause compared to person in general population discounted at 3% annually

	GP	AHP	Difference
Disability transfers	SEK431,108	SEK3,545,873	(SEK3,114,765)
Pension costs	SEK1,162,120	SEK1,162,120	SEK0
Health costs	SEK903,413	SEK29,719,622	(SEK28,816,210)
Total transfers	SEK2,496,640	SEK34,427,615	(SEK31,930,975)
Lifetime earnings	SEK6,585,922	SEK0	(SEK6,585,922)
Gross tax (direct + indirect)	SEK4,412,475	SEK1,573,942	SEK2,838,533
Life years lived (undiscounted)	57.60	57.60	0.00
Productive life years lived (undiscounted)	33.64	0.00	33.64

Conclusion

The main government cost associated with AHP are associated with attack frequency. Lifetime earnings loss and inability to pay average lifetime taxes have an impact on government tax revenue. Changes in the frequency of AHP attacks that allow people to live normal life course can have positive tax implications for government. In addition, enabling people to return to work can help save costs associated social benefit costs. The fiscal framework provides a broader public economic perspective to demonstrate a wide range of costs associated with rare diseases and like opportunities for influencing public finances.